

# Learn about ME webinar for GPs and primary care professionals

Thursday 26 September 2024

This is a summary (pages 1 and 2) and full transcript (pages 3 to 17). For more information and a link to the recording and slides, please visit

[https://youtu.be/jGN\\_BBhSz7U](https://youtu.be/jGN_BBhSz7U)

## Summary

### Introduction and speaker backgrounds

- Dr Nina Muirhead: Dermatology surgeon with personal and professional interest in ME. Developed the Learna ME/CFS learning module and served as an expert witness to the [2021 NICE Guideline for ME](#).
- Dr Robin Kerr: GP specialising in ME and long COVID, leading the local rapid cancer diagnostic service and offering consultations via [Action for ME](#).
- Webinar Moderators: Clare Ogden and Avril McLean, Action for ME, assisted with managing Q&A and polls during the session.

### Overview of ME/CFS

- ME (Myalgic Encephalomyelitis) is a complex neurological disease often referred to as Chronic Fatigue Syndrome (CFS).
- Primary symptoms: Severe fatigue, unrefreshing sleep, cognitive impairment, and post-exertional malaise (PEM)—where exertion worsens symptoms.
- Severity levels: Vary from mild to very severe, with the most severe cases being bed-bound and tube-fed.
- Diagnostic criteria: Recognise after 4 weeks in children, 6 weeks in adults, and confirm after 3 months if symptoms persist.

### Challenges in diagnosis and management

- Diagnosis misconceptions: ME is not a diagnosis of exclusion. A patient's ME diagnosis does not rule out other coexisting conditions.
- Early recognition: Proper documentation in patient notes aids in explaining their condition to employers, schools, or family.
- Management approaches:
  - Emphasise supportive management.
  - Use of mobility aids or adaptive devices as necessary.
  - Focus on conserving energy through pacing strategies, which involves balancing activity and rest.

### Impact on Quality of Life

- ME/CFS significantly affects daily activities, mobility, self-care, and social life.
- Emotional and social consequences: "Patients are really keen to get the message across to doctors that they feel anxious because they get up and they

don't know if they can manage things that day. But if they felt well, they wouldn't be anxious. It's the illness driving the anxiety, not the anxiety driving the illness.”

- Family and caregiver impact: Families face limitations on holidays, increased expenses, and strained relationships.

#### Pathophysiology and research findings

- Exercise capacity: ME patients have reduced exercise capacity, proven through lab testing showing an impaired oxygen extraction ability.
- Endothelial dysfunction: Research indicates a role of inflammation in the endothelium (inner blood vessel lining), which correlates with higher symptom burden.
- Energy production and fatigue: Impaired mitochondrial function leads to decreased efficiency in energy production, explaining severe fatigue.
- Similarities to long COVID: Many ME patients have similar physiological markers to long COVID patients.

#### Symptom management strategies

- POTS ([Postural Orthostatic Tachycardia Syndrome](#)): Autonomic dysfunction common in ME patients; management includes increased fluids, salt intake, and possibly medications like bisoprolol.
- Mast Cell Activation Syndrome ([MCAS](#)): Presents with multi-organ symptoms such as headaches, IBS-like symptoms, and skin rashes. Treatment may involve H1 and H2 blockers (antihistamines).

#### Supportive care and social considerations

- Validation and recognition: Patients benefit immensely from being believed and having their symptoms validated.
- Regular reviews: Frequent follow-ups (every 4-6 weeks) help monitor new symptoms and provide ongoing support.
- Severe cases: Severe and very severe patients require ongoing assessments and comprehensive care, including BMI monitoring for those who are bed-bound.

#### Educational and support resources

- [NICE guideline](#): Offers clear recommendations for recognising and managing ME.
- [Learn about ME project](#): promotes an [online module](#) with case examples to help practitioners better understand ME management, plus [podcasts](#) featuring patients and professionals
- Charity support: Organisations like [Action for ME](#), the [ME Association](#) and [#MEAction](#) offer resources and support for both patients and caregivers.

## Transcript in full

00:02

### Clare Ogden

Welcome everyone and thank you for joining us for this Learn About ME webinar. Your panellists this evening are Dr Nina Muirhead and Dr Robin Kerr. Nina is a dermatology surgeon in Buckinghamshire with a personal and professional interest in ME. She's done research on quality of life for patients with ME and their family members, qualitative research interviewing patients on their experiences with GPs. She was an expert witness to the 2021 NICE Guideline on ME.

00:32

and is the author of Learner's Online ME/CFS learning module. Nina has firsthand experience of ME after contracting Epstein-Barr virus in 2016. Robin was a full-time GP partner in the Scottish Borders for more than 10 years. He now continues to work in general practice, but also leads his local rapid cancer diagnostic service and offers UK-wide online consultations for patients with ME and long COVID via Action for ME.

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Among other things, this allows him to offer ME patients options based on applying evidence from medical research, which mainstream medical practice left behind. He contributes to the Scottish EVE 2 and international team clock groups researching ME and long COVID. My name is Clare Ogden and I'm here with my colleague Avril to help manage the chat and the Q&A. We'll also launch a poll towards the end of the webinar. Please answer it before you leave if you can. Please post your questions in the Q&A channel as we go.

01:29

and we'll come to these after the presentation. Robin, over to you.

### Dr Robin Kerr

Hi everyone. Thank you very much for giving up your Thursday evening. I really appreciate that and hope we can make this worth your while. When we have a complex patient in general practice, there's usually, you know, simplistically two ways of going [about that]. There's either, I don't know what's going on here and therefore you must be imagining it.

01:59

Or there is, I don't know what's going on here and I'm curious to find out more. So credit to all of you as attendees, you fall into the "I'm interested to find out more" category. So well done for that. Content for tonight, we're going to talk about what ME is, the symptoms, how to make a diagnosis and consider its management, and quality of life from Nina's research. I'll talk about the pathophysiology

02:28

and the symptom management, both pharmacological and potentially then looking at non-pharmacological and information, support and resources available. We'll then open it up to questions afterwards and be very happy to take those. So without further ado, over to Nina.

02:54

**Dr Nina Muirhead**

Thank you so much, Robin, for the great introduction and Clare as well. It's great to see some more participants trickling in, so welcome everyone. I think the most important message tonight from my point of view is that people with ME need two things, recognition and support. And I think that's what

03:23

primary care physicians can really offer. I'm really excited to hear Robin's part about more details on pathophysiology. And it's really fascinating to see what's happening. But if someone came in tomorrow, the first thing that you could do is recognise them and acknowledge what they're saying. So, ME

03:49

is a neurological disease, sometimes known as CFS or chronic fatigue syndrome. It's been recognised as a neurological disease since 1969 by the World Health Organisation. And the main thing that sets it apart from almost every other disease is the fact that people get worse

04:18

following exertion. That can be physical, mental or emotional. What happens is they get multi-system symptoms.

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There's a severity from mild to moderate, severe, and also some patients who are very severe, they're bed-bound and tube-fed.

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The main diagnostic criteria also include unrefreshing sleep, severe fatigue or exhaustion, cognitive impairment, and again, post-exertional malaise. That's another word for symptom exacerbation following exertion. And that's the key feature that you need to pick up. I'll keep saying it, recognition and support.

05:12

I've put this slide here with all of the other symptoms because I think it's really important to know that a patient might walk in and mention one of these because it's the one that's stopping them from sleeping. For example, they might be getting jerks in

their muscles or they might be getting feeling hot and cold. And that's the one thing that they attend with. So it's really important to ask a multi-system inquiry.

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How are you feeling otherwise? Are you able to work? Are you able to exercise? How's your sleep? And if you start trying to pick out some of the other multi-system symptoms that they might be getting, it will give you a picture of how impacted they are.

06:04

NICE in 2021 came out with some guidelines that suggest that you should start suspecting ME after just four weeks in children and six weeks in adults, and you should be making a confirmed diagnosis after three months. And I think that Scotland, at the moment, the best guide they have is still the NICE guidelines, and Avril will talk more

06:34

to that in the question and answer session. But the symptoms for diagnosis are fatigue, unrefreshing sleep, post-exertional malaise and cognitive impairment. If a patient has those four, you need to document in their notes, I suspect or I diagnose that they have ME. ME is no longer considered a diagnosis

07:00

of exclusion, you don't have to investigate exhaustively to suggest this diagnosis.

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And on the other hand, once you've diagnosed it, you can't then say every other symptom that they present with is down to the ME. So it's not an exclusive diagnosis and it's not a diagnosis of exclusion. A little bit like diabetes or hypertension can run alongside lots of other diagnoses. If they have these cardinal symptoms, please diagnose them

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because then they can go and tell their employers or their university or their school or their family: "I'm really ill with this condition, it's chronic and I need to rest to be able to try and recover."

07:57

Management is supportive because this is a chronic illness and people need to be able to conserve as much energy as possible to convalesce. So if they need a wheelchair or mobility aids, then they need it. Or if they need months off work, then that's what they need.

08:26

Another thing you can advise patients is how to pace and rest. This involves making sure that they're not doing too much each day and having regular small breaks, dividing up or chunking their activities so they can manage without feeling more ill.

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Initially, when a patient's got a diagnosis, it's probably worth seeing them every four to six weeks if you can, or at least telephoning them to see how they're getting on. And warning them that if they get any new symptoms, which they haven't previously experienced, to make a note of them and maybe present back again.

09:21

Robin will get onto the more detailed options for treating some of the symptoms. I did some research with medical students at Cardiff University, and they interviewed 10 patients about their presentation with ME and how they first went to their GP. Not one of them said they had fatigue.

09:49

Not one of them said they were tired. Most of them said they felt ill or they couldn't go on or felt like they were dying. That's how they first presented. I'm going to read a couple of these examples from the interviews. This is unpublished research but we had ethics approval and we hope to publish soon. A teacher said: *I was working,*

10:20

*I was starting to feel really ill, but I was pushing through. And then one day I decided to jog back home from school. The next day I totally collapsed and felt like I was dying.* Another patient said: *you feel ashamed. You can't live your life the way you want to.* In fact, most patients said they often underestimated how ill they felt to both their families and their doctors

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because they didn't want to sound like hypochondriacs.

10:54

Here's a few more quotes: *I was too ill to continue.*

11:05

*I got the flu, went back to work, then started getting pins and needles and other symptoms.* Many patients bounce in and out of work.

11:16

One said: *I thought I was slipping away. I felt so ill. Things can sometimes hit me for days or weeks at a time. My neck would get really stiff, tremendous headache and fever. The next time it happened, I thought, oh well, I didn't die last time. I kept going to the GP and*

*saying, I'm not well. I'm not well. I had pneumonia and I wasn't getting better and I wasn't getting better.*

11:48

So post-exertional malaise, I experienced this first hand and it took me about three months to recognise what was going on. Having previously run half marathons at the weekend and then done a normal week's work, maybe ate a bit, it was quite bizarre to go to the corner shop and then be in bed for three days from 100 meters walk.

12:18

So instead of asking, do you have post-exertional malaise, the patient won't necessarily realise. It's worth asking, what could you do a year ago or six months ago, or even before you got ill? Some patients won't necessarily present with a specific flu or COVID or illness, but they may have a deterioration over months. So you say, when were you last well

12:48

compared to today, what percentage are you functioning at? Even children as young as nine have been able to give me a percentage of how they're functioning compared to before. Or you can ask more specifically how many hours a day or week can you productively function? At my worst, it was about six hours a week I was productive – and that was being able to eat

13:18

and talk and the rest of the time I couldn't do anything.

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One that's quite often used over in the US is “How many hours are your feet on the floor?”

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to gauge how severely they're affected. And what happens when you do engage in normal previously tolerated exertion? Do you avoid or change certain activities because of what happens after them? And what can and can't you manage on a good or bad day?

13:56

Sometimes people will feel ill for a few hours or maybe a day after doing something, but some patients will take weeks to get better from exertion. I'm just going to quickly mention before I hand back over to Robin, a little bit of the quality of life research that we've published. In 2022, we published [in the BMJ](#) and then just in July this year

14:24

[in Medicina](#) about the quality of life impact. Over 2000 patients responded, and their family members.

14:36

Most people were impacted on their ability to do usual activities, but also quite highly impacted in the other domains of pain, mobility and self-care. Despite being as ill as they were, patients reported least that they were anxious, compared to quite a lot of other disease states.

15:01

Often patients are really keen to get the message across to doctors that they feel anxious because they get up and they don't know if they can manage things that day. But if they felt well, they wouldn't be anxious. It's the illness driving the anxiety, not the anxiety driving the illness.

15:24

And family members... when I see a patient with dementia, I often turn to their family member who's usually had to attend with them to the clinic and say, how are you coping? Or any other diagnosis of major cancer or motor neurone disease. And I think for people with ME,

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you need to turn to their family members and say, how are you coping? And you need to offer them support as well.

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Compared to a lot of other diseases, ME impacts family members significantly. People's family members say they feel worried, frustrated and sad. And they're really impacted on what family activities they can do. Often they don't go on holiday for years. And their expenses and sex life are also impacted. I think it's really important to acknowledge that.

16:25

I'm going to hand back over to Robin now and thank you for listening.

16:31

**Dr Robin Kerr**

Thanks everyone. Thanks Nina, that was really good. Even as someone who does this every week, that was still very informative. So thank you.

16:49

[video cuts out]

16:57

We're going to talk about pathophysiology now, and I've picked this picture. What I'm going to present to you is pieces that we have. There are pieces that we don't have.



There are multiple different people contributing to the jigsaw. But in order to be able to help people, I'm a great believer that we take a look at what pieces we have and how they join together, rather than waiting till we've got the whole puzzle and then going:

17:27

“Oh, I wish we'd done something about that sooner.” What I'm going to present to you is not the complete picture, but I think it's really important we make use of the puzzle pieces we do have.

17:44

ME patients have a reduced exercise capacity on day two controls capacity increases. What that means about post-exertional malaise and post-exertional symptom exacerbation, in a lab setting this has been shown to be biological and not psychological.

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And so any preconceptions or stereotypes or outdated ideas that have previously circulated about this condition, these studies really, really put them to bed

18:34

(my youngest child just walked in on me there then, sorry, she's needing to get put to bed). So we put people on exercise bikes and measure what they can do aerobically and where they hit the threshold to become anaerobic. And then we get them to do it again on a second day

19:04

[video cuts out] The control group all do better on a second day, because that's what humans do, they get better with practice – but not people with ME.

19:18

This is lab-based proof of patients getting worse with activity, their cardiovascular capability getting worse with activity. ME patients have an elevated blood lactate at rest

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and are at higher risk of more severe post-exertional malaise. So, I was already saying in that previous slide that these people have a lower threshold to become anaerobic.

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They therefore run with a higher blood lactate than controls. And lo and behold, the people with a higher lactate at rest are more likely to get more severe symptom exacerbation if you push them to do things. On the left [referring to slide], we're just dipping back into high school biology and the Krebs cycle, really efficient energy production when we've lots of oxygen going around.

20:23

36 ATP, really inefficient energy production if we've not got enough oxygen going around only 2 ATP for the same input... and so showing here why these people are so exhausted to do the absolute basics of life because they're doing it in a more anaerobic environment where their energy production

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is compromised. Just from these studies, we're already starting to understand the fatigue and we're already starting to understand the post-exertional malaise.

21:06

A reduced VO<sub>2</sub> max in long COVID patients is from a peripheral rather than central cardiac limit due to impaired capillary oxygen extraction and not deconditioning.

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My toes curl whenever I hear people say that long COVID patients are just deconditioned. We've had people with long COVID that were due to compete in the Tokyo Olympics and then couldn't. They didn't become deconditioned because they spent a week in bed. It's going back to the lab studies. We've proved that it's from a peripheral

21:54

oxygen extraction issue. What they've done here is they've done that same cardiopulmonary exercise testing, but they've stuck a venous catheter into these people. So they're measuring the oxygen return to the right side of the heart. And they're able to say that this isn't a cardiac impairment, this isn't a fitness impairment, this is an inability to extract oxygen

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from their peripheral circulation. And so then here's another piece of jigsaw to say, well, that'll be why they're ending up in this anaerobic, high lactate situation. They can't extract the oxygen out of their bloodstream the same way as healthy controls. And there's a truckload of other papers that I've summarised there on the right as well, showing the same thing.

22:49

What these studies together do is offer us a potential explanation for the post-exertional symptom exacerbation or post-exertional malaise that Nina has highlighted as a key part of the diagnostic criteria for ME. I'd like to share an analogy here that I regularly share with my ME and my long COVID patients and they tell me it's useful

23:16

both in terms of helping them to understand pacing, but also helping them to maybe explain to family or friends or employers that otherwise don't get it. Because whilst not everybody's walked a day in their shoes, every one of us has had to get by with a smartphone when we're low on charge and a long way from a charger. So if you imagine their

23:46

life, their body, is like a smartphone that just charges to 20% overnight. And if previously you used 5% to get washed, 5% to get dressed, 5% to make your breakfast, you're off to work with 85% still in the bank and you don't even notice that you've used that 15%. But if you do those same three things on a 20% charge,

24:15

your battery light's critically flashing and it's only nine o'clock in the morning. And so the smartphone analogy continues because they then have to be so tactical about how they use their apps. They can still go into the news app but rather than read the in-depth article that the investigative journalist has spent months compiling, they just check the headlines. Rather than go into the weather app and look the forecast for the next week

24:45

they just check the forecast for the afternoon. And that's pacing: using finite energy reserves in a tactical way to try and allow them still to be the basics of being them, which, you know, to use Nina's example, the basics are being able to eat and put some calories in the system, the basics are being able to speak...such is the level of disability that this illness can cause.

25:13

I try and always share this analogy because it helps maybe to understand a bit about what it's like for these people and to help them understand how their body works and how to pace accordingly.

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We talked before about what could be a peripheral, this peripheral oxygen extraction, why could this be? Well, we've got evidence in ME that it's endothelial dysfunction. And so if we remind ourselves of anatomy, the endothelium is the inner lining of the blood vessel. And endothelial

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inflammation correlates with symptom burden. If we look at markers of endothelial damage in ME and long COVID patients, the higher the markers of endothelial damage, the higher their level of symptoms and the worse they do from an exercise tolerance point of view. And so again,

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I said at the outset, I don't have all the jigsaw puzzle pieces here, but you can see how these are all starting to fit together here, and bits of science here and bits of science there are starting to add up. We're appreciating that those with the most inflamed endothelium are those that do worst from a symptomatic point of view. I would propose that that is not a coincidence. And I would certainly

26:56

roll up the papers and gently bat around the head anybody that still wants to suggest that these people are *thinking* they are endothelium inflamed, because that's just not true.

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What does the endothelium do? Well, it's a barrier on a membrane for stuff coming in and out of our blood vessels. We've already highlighted that means you then struggle to transport oxygen across the same way, and the reduced exercise capacity. Impacts then on vascular tone...

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...Clare, if you maybe could just clarify, can people see me okay on the screen if I'm holding my hands up here? Is that how we've set the...

**Clare Ogden**

Yes, you're absolutely clear.

**Dr Robin Kerr**

Thank you. So if we imagine our sort of sympathetic nervous system, we've got our fight and flight sympathetic, and we've got our rest and digest parasympathetic. The parasympathetic fibres are embedded deeper into the blood vessel

27:59

than the sympathetic. So the parasympathetics are more susceptible to that endothelial inflammation from that inner layer of the vessel. So rather than these two things being kind of yin and yang as they're meant to be, you've got an imbalance, and you've got too much fight and flight going on with unopposed sympathetic, and not enough rest and digest, in these people that are already exhausted. And so they're stuck, tired but wired.

28:30

Your endothelium behaves naturally. If it's inflamed, it thinks it's under attack – and usually it's under attack if you cut yourself – it's part of the inflammation response is to become more clotty. And so you get coagulopathy, hyperactive platelets, micro emboli, which then can occlude our smallest capillaries

28:59

and make that oxygen transport situation even worse. Embedded in the lining of the blood vessels in that endothelial layer, we also have mast cells. Mast cells contain lots of histamine. Histamine is the allergy chemical. And so mast cells react to the inflammation by getting irritated. And when they get irritated, they dump their contents into the blood. We'll talk in subsequent slides

29:29

about the relevance of that to how they present. And then inflammation, I mean, the clue was in the original name, myalgic encephalomyelitis, like the 'itis' bits been there at the start, but it's maybe been hijacked by some people to suggest chronic fatigue syndrome and it's a psychological inference from that, but there's always been inflammation. The reason they've got the cognitive impairment

29:58

is inflammation. The clues in the name, it's just that we're lagging a bit behind when it comes to treating it. So, symptom management. These are some of the things that I do in general practice and I feel comfortable doing. I realise if this is new and unfamiliar it might not feel entirely comfortable to you, but

30:29

part of the purpose of this presentation this evening is that we hopefully do make it familiar and we do make it comfortable.

30:38

Autonomic dysfunction – great little infographic there on the left [of the slides] – people that are presenting dizziness, palpitations, chest pain, presyncope, memory problems, short of breath, gut problems, excessively tired, feeling sick, sore muscles, headache, insomnia. Little wonder the average POTS patient takes seven years to be diagnosed

31:04

and has been told they're anxious for most of those seven years. Remember they're stuck with too much sympathetic going on. So, of course, they present as kind of a bit anxious, but that's because their sympathetic nervous system is imbalanced. You can test for that with a NASA lean test.

31:28

We're going to share the slides the web links there. There's a [great little four page summary](#) from the Bateman-Horne Center, which is one of the great places to treat ME in the US. Great little summary of how to test for this in general practice. To do a good NASA lean test, you need them supine for 15 minutes. Not always practical or possible to do that in a busy primary care setting. So often I'm getting people to use a blood pressure cuff

31:57

and a well-meaning friend or family member to do this with them at home and then reviewing the results because it's not really realistic or practical to have them supine for 15 minutes before you stand them up in primary care. When you do stand them up, the pictures there are showing dependent acrocyanosis – again, another thing is that you can't think your legs change in colour – so we need to really get on board this is biological.

32:28

In terms of treating autonomic dysfunction, usually we're then given more fluids, we're given more salt. We are absolutely not saying that these people need to exercise themselves better. That's totally outdated, that's totally gone. The notion of graded exercise therapy is completely debunked. The research on it is completely debunked. We're not suggesting these people exercise themselves back to health

32:57

but they can do some recumbent exercises to try and improve muscle tone, venous return and therefore symptom control. [POTS UK](#) is a great website for advice on diet and exercise and these recumbent exercises. You want to stop medicines that are detrimental to autonomic nervous system function. There's a nice little summary here. Rate limiters, so once you've done your ECG, you've excluded anaemia, you've excluded hypothyroidism

33:27

with pheochromocytoma if you're really finding other reasons to think in that direction, but not routinely. I usually start these people in bisoprolol and only 1.25 milligrams and for some people that can be absolutely life changing. It can take people from bedbound or close to bedbound situations to talking about

33:51

going back to work and going back to exercise. And if you find the condition and you treat it, it can make such a difference. Compression garments as well, so prescribed by us, class two or class three compression, it gives the legs a good old squeeze, again, trying to enhance that venous return. POTS on a page, nice little summary here, you'll find that on the POTS UK website.

34:19

Mast cell activation syndrome: here's another set of multi-organ symptoms where people could so easily be fobbed off as anxious. They're presenting with headache, they're presenting with ENT irritation, they're presenting with IBS type stuff. But then they've maybe got some rashes as well, but it's all the allergy driven stuff. So usually, when I'm screening for this, I'm checking for your hayfever type symptoms,

34:48

IBS type symptoms and some, you know, kind of rash type stuff as well. But these people as well, you'll find that potentially they've then got issues with things they used to go on fine with like foods they used to be able to eat fine and now a real problem. New intolerances typically to processed foods, which are high in histamine and also carbohydrates, which are, which are high in histamine.

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Great study done in London: they took a cohort of long COVID patients and they, for at least a month, gave them both an H1 blocker in loratadine or fexofenadine and also an H2 blocker as well. And the crucial bit of that is that when you've got all this excess of circulating histamine, if you just block H1, your H2s are still going nuts.

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If you just block H2, vice versa. So you need an H1 blocker and an H2 blocker. And in doing that, 20% of long COVID patients reported symptomatic resolution, 52% reported some improvement. Antihistamines, I mean, low risk for potentially high reward. It's clearly not going to work for everyone, but if you have any inclination that you're seeing evidence of mast cell activation,

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why not fire them a couple of antihistamines for three months? Give it a try. Okay. Really happy to talk about more of this, but I'm mindful that time's ticking on, so I'm now going to hand you back over to Nina. Thank you.

36:40

**Dr Nina Muirhead**

I thought that was brilliant, Robin. Thank you. I also try some sodium cromoglicate before meals if there's more sort of a gut histamine effect. I definitely have seen that help a few patients.

37:05

Sorry, I realized I was on mute there. Now onto the support part of what ME patients need.

37:16

They need someone to listen to them. Often they'll have seen lots of people before they land in your office. And I think it's really important to listen to and acknowledge what they're saying. One middle-aged chap who was previously very fit was finding that he was exhausted for three days from peeling the potatoes for the family meal. And

37:44

the psychiatrist used that as an example as to why he was clearly imagining his symptoms. But if you could just imagine for a moment how limited you would feel if just peeling potatoes or just cleaning your teeth meant that you felt ill for three days. I think it's really important to be

38:14

super compassionate and just believe what people say. And if there's nothing else you can offer them, having that validation and having someone just acknowledge how well they must be is very, very vital to enabling the patient to start asking their own network of support for care. And that takes the pressure off the medical system.

38:45

I talked about regular medical reviews before and it's helpful to have some continuity if possible as well as mobility aids. But some people with ME/CFS can be very severe and they will need full-time care and they will need assessing. They need help with personal hygiene and

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they need regular assessment. If they cannot get out of bed to be weighed, their upper arm needs to be measured to get an idea of their BMI because these patients can be very sick indeed, and some patients will die.

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So be super aware: it's rare, but it does happen. And you need to be involved and on it and get as much help as you can from the district nurses, from any help you can, ambulance team, to assess these people if they're deteriorating.

40:01

Sorry, I keep putting mute instead of scrolling on.

40:10

I'll keep this very brief now because I think we should move to question and answers, but the main point of this whole slide is when you do involve social care, it's not so they can be reenabled, it's so they can keep their energy requirements to the minimum.

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and so they can have a care plan and the support that they need. They're not trying to rehabilitate. They're not supposed to be challenged by any social care workers to go further each day or do more each day. This is so they can do less and conserve that energy so that they can start to rebuild



41:10

and convalesce.

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So if you're stuck, the NICE guidelines are very helpful, particularly when it talks about getting aids for helping people, but also being proactive and flexible about either telephoning patients or trying to do a home visit if you can. And I know resources are tight, but a stitch in time saves nine and a follow-up phone call

41:48

to a patient who is severe or very severe might be very important.

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So we've been working hard to help educate people, particularly in Scotland, as part of the [Learn about ME project](#). And all of these slides will be available so you can click on the links and resources. And please do the [online module](#). It's got 10 case examples. And it's got all the resources and links to the publications.

42:21

I think a lot of GPs feel a bit vulnerable that there's no one to refer to, and we'll talk about that in a moment, but the charities are excellent... because patients are so desperate they've been working quite closely with their charities to give them as much information as possible, and they've gathered that information and they've found what's helpful and what's not. So if you're really stuck, please do use these charity

42:51

resources [[Action for M.E.](#), [ME Association](#), [#MEAction Scotland](#) and [25% ME Group](#)] because they're incredible and better than any other disease I know, mostly dermatology and there's some incredible dermatology charities as well.

43:04

Thank you for listening.